Interaction Design Project 3

Information Management system to support HIV patients & Doctors

By:
Kirti .H. Kanitkar
(08633006)

Guide:
Prof. Anirudha Joshi

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Approval Sheet

The Interaction Design - Project 2 entitled "**Information Management system to support HIV patients & Doctors**" by Kirti .H. Kanitkar is approved, in partial fulfillment of the requirements for Master of Design degree in Interaction Design.

Guide:

Chairman:

Internal Examiner:

External Examiner:

Declaration

I declare that this written submission represents my ideas in my own words and where others' ideas or words have been included, I have adequately cited and referenced the original sources. I also declare that I have adhered to all principles of academic honesty and integrity and have not misrepresented or fabricated or falsified any idea/data/fact/ source in my submission.
I understand that any violation of the above will be cause for disciplinary action by the Institute and can also evoke penal action from the sources, which have thus not been properly cited, or from whom proper permission has not been taken when needed.

Signature

Name of the student: Kirti H. Kanitkar

Roll No: 08633006

Date: 7th June 2010

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Kirti .H. Kanitkar,
June 2010

Content

1.0 Overview

1.1 Abstract

The needs of the PLHA (Patients living with HIV/AIDS) in India today, facilitates designing better interactions between the Patients and Doctors, so that Patients could be informed and updated about their current status and the doctors are also updated with the same.

There needs to be interaction between them, so as to track the health details and providing medication is concerned. Patients also have certain other issues with the management of expenses, or side effects due to HIV medication and providing quick help or access to the doctors is necessary.
On the other side, doctors face problems in tracking and analyzing details of the patients and managing the patient information. Thus there was a dire need for an automated system that would help the user's to resolve these issues and help them cope up with the HIV medication and issues relating to it.

The report describes the design of a mobile application "Life Plus" that is personal (as it is on cell phone and is password protected) and easy to use Icon based application that highlights important features of Reports, History, Reminders, Expenses, side effects & Speak up which would support the HIV patients and keep them updated about their status and the design of a software application for the doctors, which helps them, analyze the data and stay connected with the patient and their health information.

The project went through the process of design, prototyping and user evaluation. These applications facilitate improved interactions, and also present the information that is important for the patients and doctors in the best possible way.

2.0 Introduction

2.1 About HIV

HIV stands for Human Immunodeficiency Virus (HIV). HIV is a virus, which replicates by destroying white blood cells in the body. There are no proven facts about the origin of HIV, but the earliest know case of HIV was from a blood sample collected in 1959 [1] from a man in Kinshasa, Democratic Republic of Congo. (The cause of infection is not known.) Genetic analysis of this blood sample suggests that HIV-1 may have originated from a single virus in the late 1940s or early 1950s. [1]

The human immune system protects the body by attacking the viruses & bacterias entering it by destroying them. But as the HIV virus is damaging the immune system, the body becomes susceptible to illness and infection giving rise to opportunistic infections like Tuberculosis, Herpes zoster etc.

2.2 Statistics

Statistics show that people living with HIV/AIDS in 2008 in the World are 33.4 million estimated ie 31.1-35.8 million (range)
In which the Adults are 31.3 million, Women are 15.7 million
and Children are 2.1 million. [2]

The 2006 estimates Adult HIV prevalence in India is approximately 0.36 percent, amounting to between 2 and 3.1 million people. If an average figure is taken, this comes to 2.5 million people living with HIV and AIDS; almost 50 percent of the previous estimate of 5.2 million. [3]
More men are HIV positive than women. Nationally, the prevalence rate for adult females is 0.29 percent, while for males it is 0.43 percent. This means that for every 100 people living with HIV and AIDS (PLHAs), 61 are men and 39 women.
While adult HIV prevalence among the general population is 0.36 percent, high-risk groups, show higher numbers. Among Injecting Drug Users (IDUs), it is as high as 8.71 percent, while it is 5.69 percent and 5.38 percent among Men who have Sex with Men (MSM) and Female Sex Workers (FSWs), respectively. [3]

The geographical break-up shows, 118 districts have HIV prevalence more than 1 percent among mothers attending ante-natal clinics. The 2006 estimates indicate that, new areas have seen a rise in HIV prevalence, particularly in the northern and eastern regions. 26 districts have been identified with high prevalence, largely in the states of Madhya Pradesh, Uttar Pradesh, West Bengal, Orissa, Rajasthan and Bihar.

There is a significant population living with HIV and AIDS among IDUs (Injecting Drug Users) in four of India's biggest cities – Chennai, Delhi, Mumbai and Chandigarh. Young people are at greater risk, (as they get carried away with the surrounding and are influenced by others) with the age under-15 accounting for 3.8 percent of all HIV infections, as against 3 percent in 2002. [3]

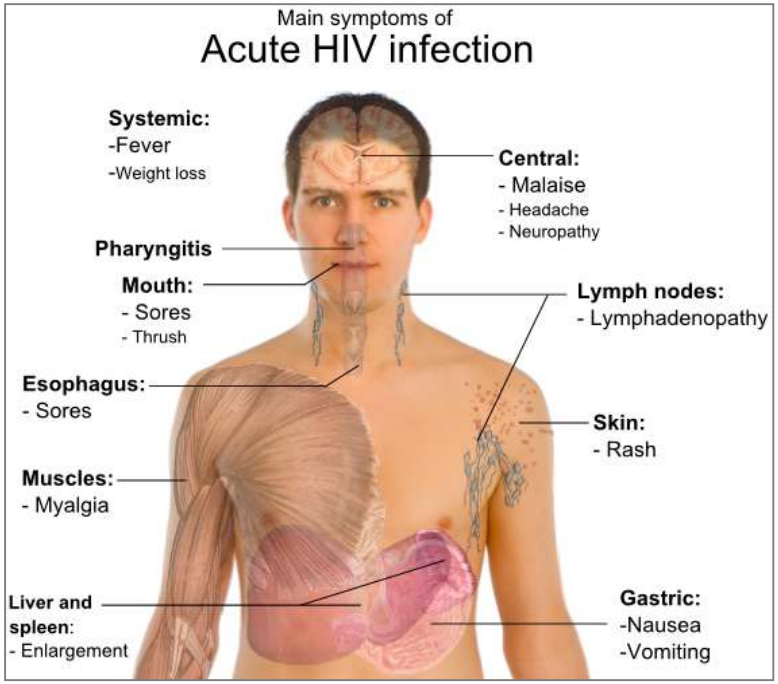


Figure 1: Symptoms of Acute HIV infection [4]

2.3 Signs & Symptoms

Typically the HIV infection causes progressive decrease in the CD4 (T-lymphocyte cd4+) cell count and increase in the viral load (amount of Virus). Most of the times the signs & symptoms look quite common such as fever or cough and so doing a HIV test becomes important.

Some of the signs of HIV infection:

- Swollen glands in the armpits, groin, or neck
- White spots or unusual marks in the mouth or throat, or on the tongue
- Red, brown, pink, or purple blotches on or under the skin. Blotches can also be inside the mouth, nose, or eyelids
- Fever that will not go away
- Pneumonia—a disease that causes the lungs to fill with fluid [1]

Some of the symptoms of HIV:

- Losing a lot of weight without trying
- Dry cough
- Sweating a lot during the night
- Feeling very weak or tired for no reason
- Diarrhea that lasts for more than a week
- Memory loss
- Depression [1]

2.4 Transmission

Causes of transmission of HIV

- Primarily by exchange of body fluids such as blood, semen, breast milk and vaginal secretions. In general, if infected blood comes into contact with any open wound, HIV may be transmitted.

- Through sexual contact. The majority of HIV infections are acquired through unprotected sexual relations.

- Sharing needles when injecting drugs

- The transmission of the virus from the mother to the child can occur during pregnancy, at childbirth or via breastfeeding.

Figure 2: HIV Medicines

2.5 Treatment of HIV

There is currently no publicly available vaccine or cure for HIV or AIDS. There are various kinds of medicines available which are tried and tested on patients in various combinations that best suites them. These medicines typically have some or the other side effects that the patients are informed before hand.
Typically the patients are given vitamin tablets to keep the CD4 in control and when it crosses the range of 250, the ART regimen is started for the patients.

ART (antiretroviral drug treatment) is available; doctors assess their patients thoroughly, measuring the
1) Viral load,
2) How fast CD4 declines and
3) The patient's readiness.
Then they decide when to recommend starting the treatment. All the currently licensed antiretroviral drugs, namely AZT (Zidovudine), DDL (Didanosine) and NRTI (Nucleoside analogue), have effects, which last only for a limited duration. In addition, these drugs are very expensive and have severe adverse reactions while the virus tends to develop resistance rather quickly with single-drug therapy. There are combinations of these medicines that are tried out on the patients by the doctors depending on which suites them. ART neither cures the patient nor does it uniformly remove all symptoms.

The reasons for non-adherence with ART are varied and overlapping. Major psychosocial issues, such as poor access to medical care, inadequate social supports, psychiatric disease and drug abuse

contribute to non-adherence. The complexity of these ART regimens, whether due to pill number, dosing frequency, meal restrictions or other issues along with side effects that create intentional non-adherence to pill taking behavior also contribute to this problem. Typically in Indian context patients are seen forgetting to take medicines due to festivals or some occasions or avoid taking them in the public, due to stigma issues and at times due to non-disclosed status of HIV to their family members and friends.

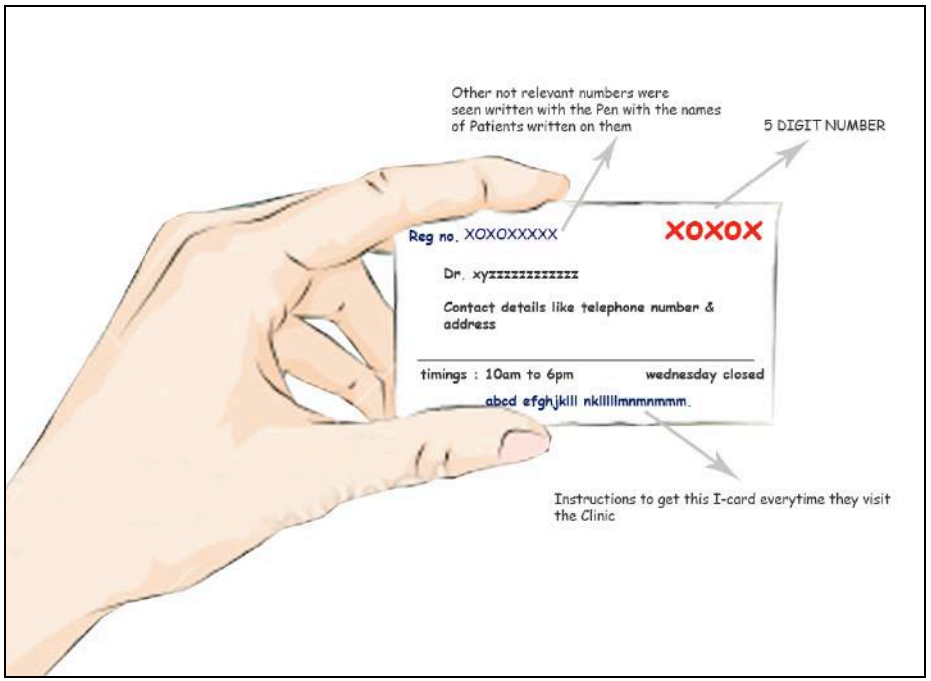


Figure 3: Object model of I-card given to the patients on ART

2.6 Side effects

ART (antiretroviral drug treatment) causes various side effects. Side effects occur when the drugs affect the body in ways other than those intended. Most of the antiretroviral drugs have known side effects, and it depends on the individual persons body, how it reacts to the drug. For some PLHA side effects occur so strongly that they have to consider alternative drugs.

Side effects can be time bound as

- Immediately life threatening – these can be fatal,
- Short term (acute)- Occur within first few months of beginning the therapy and they can affect antiretroviral adherence
- Long term (chronic) – these can occur at any time

Mild ones would be those, which would include, vomiting or nauseatic feeling in a day where as extreme ones are those that would result to hospitalization. Side effects reduce depending on the PLHA being on treatment for a while as; the body starts adjusting to the antiretroviral drugs.

Some people use alternative therapies like Ayurvedic medicines and medications with combination therapy to ease the side effects. For example, ginger to ease nausea. [5]

3.0 Goal of the Project

The Goal of the project

For the Patients:
To provide a support system for HIV +ve people and to build a system that would make them aware about their current status by keeping them updated with the important information, ie. Medical records, prescriptions, reminders for medicine, in emergency providing assistance to patients and also keeping track of their appointments.

For the Doctors:
To build a supporting system that would manage records, patient's history, complaints, side effects etc. A System that would help them analyze the patients data quickly and make the patient and doctors interaction better and easier.

4.0 Methodology

The goal was to help the Patients and Doctors to manage their information and keep them updated. The first step of the design process doubtlessly, was to understand HIV, the process involved in the treatment and the Users (Patients & Doctors). To be successful, systems must be designed with their environment and users in mind. It should also be evaluated to confirm that they do not disrupt the user's natural workflow. Well-established techniques for understanding users and their environment exist, but they are not specifically designed to assess how well the computing and physical task environments blend.

The methodology followed during this project is as described below:

- An understanding was obtained about HIV and the process involved in its treatment, its origin, existence, and acceptance value and how it takes place in the current scenario.
- User interviews were done to understand the user requirements. These were done, in Hospitals (Private clinics & Govt.) treating HIV, NGOs involved and the patients who were diagnosed HIV and suffering with the same.
- Data collection, idea generation and analysis were parallel.
- With every insightful information collected, concepts were generated which gave rise to new information requirements for which again data collection was carried out. It also became useful to set up goals for the project.
- Based on user feedback, prototypes of some of these concepts were developed. They are again evaluated with users.
- Finally various strategies were integrated to develop the final

concept. This was again prototyped and evaluated with users.

- The whole project was documented in the form of this report and presentations at various stages were made.

4.1 Target user

The initial processes of data collection included studying about HIV, brainstorming and trying to connect with the people involved, like PLHA, doctors, counselors and NGO's. Understanding about HIV and the process of diagnosis, how the treatment of HIV takes place and the treatment is followed.

By studying the NGO's, Government hospitals and private clinics treating HIV patients gave an idea of the profile of users who are HIV positive and how it is important for them to organize and manage the information.

The target group of user's was thus decided, as the PLHA and the doctors too, who needed to have very organized data and also analyzing the data across the patients, interacting and providing help whenever needed was the utmost thing involved in it.
Patients and Doctors needed different kinds of information and also the data had different organizing structure.
Counselors were not considered as target users, as they primarily worked for creating awareness, and helping out in family disclosure issues, etc.

4.2 User studies

User studies consisted of doing contextual enquiries in various Government Hospitals, Private clinics, and NGO's. Conducting interviews of Doctors, Patients and Counselors. As it was a lifelong disease involving lot of social stigma, and disclosure issues certain problems related to data sharing did occur at certain instances.

The types of studies conducted during the project can be listed as:
- Contextual user interviews
- User observation and field study
- Literature review
- Product/prototype and other similar systems

4.3 Contextual interviews

During the process I visited various Hospitals, and had a discussion with Doctors, to acquire information related to management of records. Studying their existing system and if they faced any problems using it. I tried to gather information of how people are counseled about HIV and if the users have knowledge about their HIV status (having information of their current CD4 counts/ Viral load counts and test results, etc.)
I interviewed few PLHA, to understand their knowledge about HIV, how they managed and organized the reports and if they had any problems understanding it. Managing appointments, remembering their complex regimen and expenses were some of the issues that they were facing.

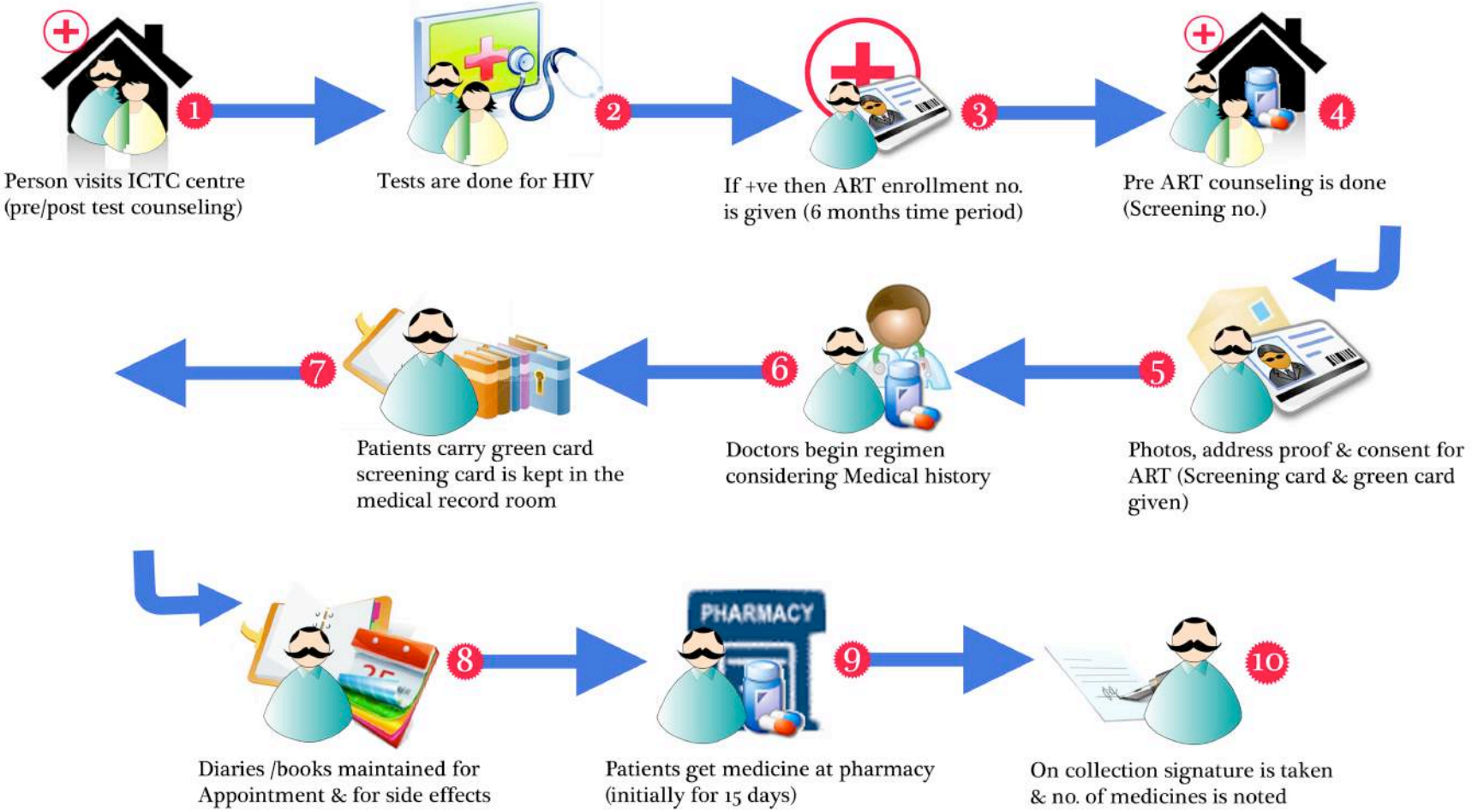
For this study 10 PLHA's were interviewed, with 3 Doctors and 2 counselors and their experiences and problems were identified, so as to come up with effective design ideas and solutions. Documents those were maintained by the Doctors & Patients were studied, so as to understand how the records are organized. Information about the Process of diagnosis of HIV and its treatment was thus collected.

The Contextual enquiry strongly suggested how the need to develop a management system /device or application was very important considering the lack of information amongst the users ie Patients and the need of organizing and interacting with PLHA's among Doctors.

5.0 Initial Research about Patients and Doctors

5.1 Process of HIV diagnosis & treatment in Government Hospitals

Figure 5



5.1 Process of HIV diagnosis & treatment in Government Hospitals

As shown in the Figure 5 the first step is that a person visits the ICTC centre (this is a counseling centre) or a Private clinic. In govt. hospitals Pre test counseling is done which is generally not conducted in a Private clinic.

After the HIV test is taken (step 2) a post test counseling is done, to prepare him psychologically for the results if they are positive/ negative and precautions for the future are instructed.

After keeping a check for 6 months period (CD4 count & health is monitored for the specific days as in that period the tests are redone as there's a possibility of false test, etc.) the patient is enrolled for ART according to his health status. Here an enrollment number for ART is provided in a govt. hospital. (step 3)

Further the patient and his family members are told to visit the centre for Pre –ART counseling. (step 4) Here the patients and family members are counseled for the life long medications to be taken. Typically they are explained the concept of ART and the importance of taking medication. How the regimen should be followed and the concepts of CD4 & HIV virus are explained to them. All the details regarding transmissions, precaution to be taken, nutrition related information is given to the patients. They show 'Flip charts' which have illustrative concept of "CD4" as 'Soldiers' and "HIV virus" is the 'Enemy'. Further, a screening number is provided to them.

Photos, address proof and consent for ART is taken from them. They fill up a postcard containing the address of the patients so as to follow up patients if they don't continue ART. (step 5)

The patients are provided with two different kinds of cards,
Screen card (contains detailed information which is kept with the hospitals) & the Green card (ART book that contains details of CD4 counts and next appointment dates with the doctors)
Further considering a patient's history a regimen is started. (step 6)
Generally patients carry the screen card i.e. the book that has entry for CD4 counts, viral load, appointments etc. and green cards are kept in the Medical record rooms of the hospitals. (step 7)

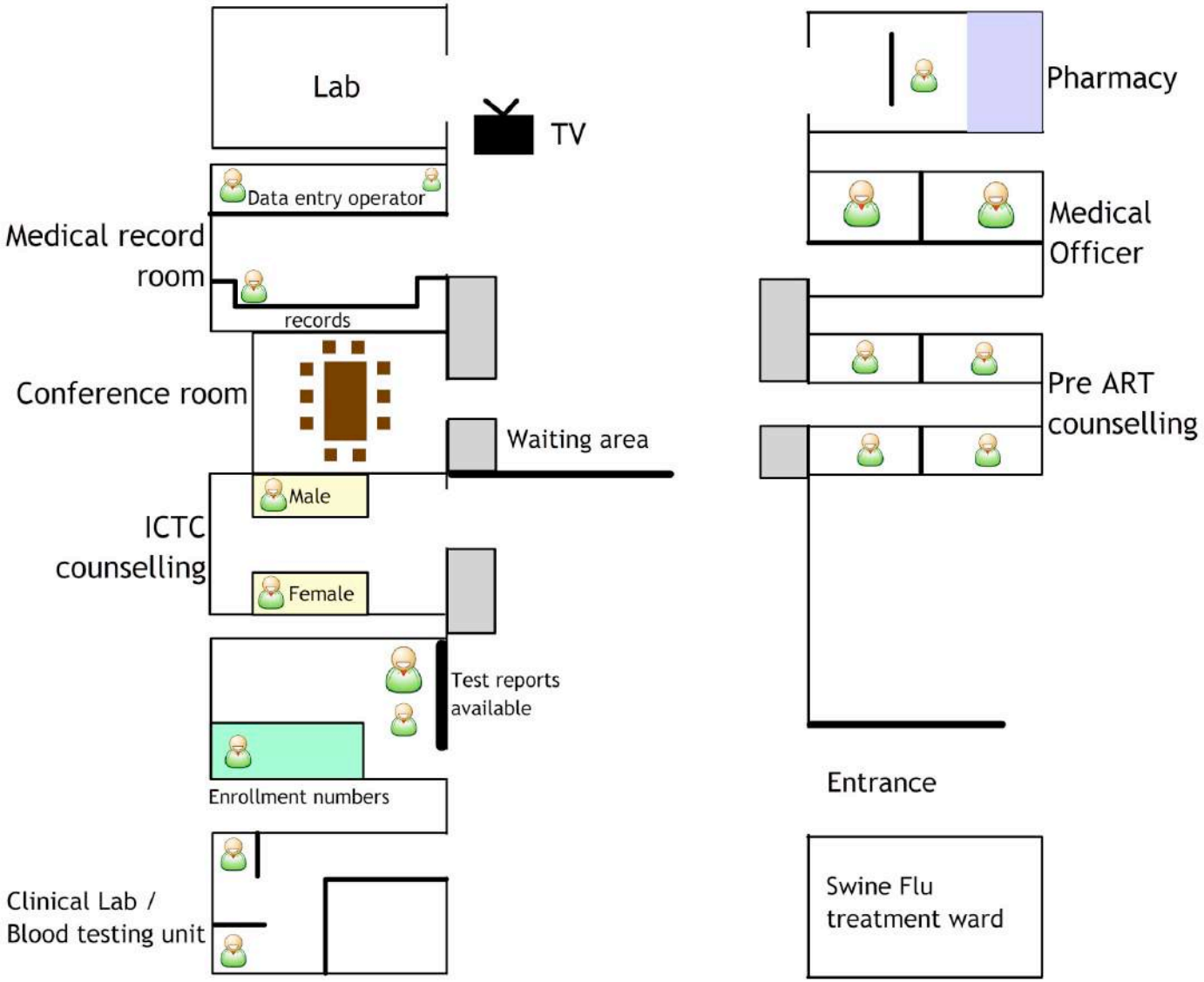
Doctors encourage patients to use diaries or books to maintain details about the side effects those are caused or even to note down the appointment details or any other psychological issues if any. (step 8)

After the medicines are prescribed to the patients, they go and collect it from the Pharmacy room in the hospital (step 9) These medicines are given for 15 days initially and when they are suited to a patient the regimen is continued. On collection of medicines, the patients signature is taken. Also the total number of medicines given to the patient is noted down on the register.
(step 10)

This ART treatment is completely free in Government hospitals.

5.2 System Design in Government hospitals

Figure 6



5.2 System Design in Government hospitals

The Figure 6 suggests the structure of typical government hospital. It was generally crowded and consisted of charts/ statistics related posters displayed on the wall.

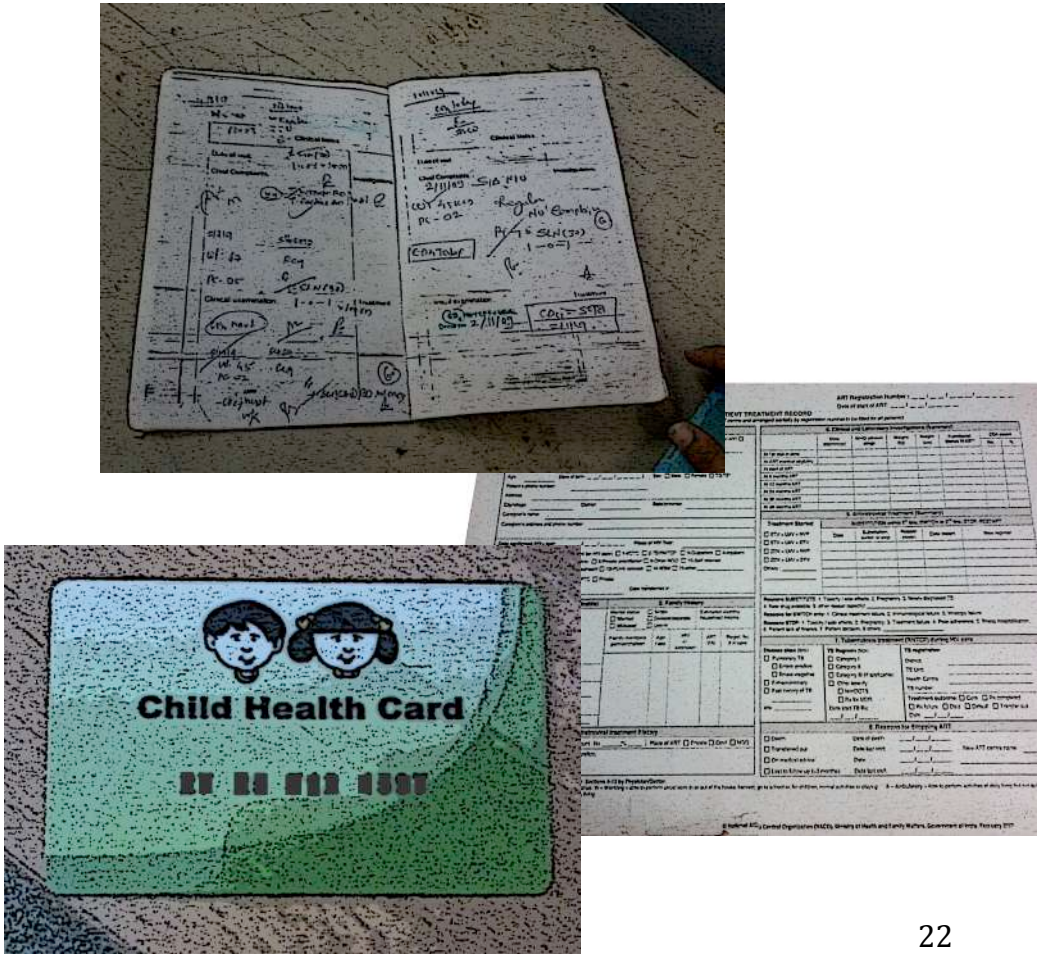
As mentioned earlier in the Figure 5 the process of diagnosis and treatment of HIV was complex and primarily would take 2 months for the patient to be registered and prescribed on ART.

The patients were given ART book (green card), which they had to carry every time they visited the hospital. The screen cards were stored in the medical record room. This would make it complex to be searched by the care coordinator, which also resulted in the screen cards being lost. The children were given I-cards and ART color books so that they could take medicines and fill up colors according to the regimen.

NACO (National Aids Control Organisaton) has CMS (Controlled management system) system designed – Adults & Pediatric Antiretroviral treatment (ART) record. This system was exactly similar to the printed screen card, present in the hospital.
It consisted of Identification data, Personal history, Family history, ART history, Clinical & lab investigations, ART summary, TB treatment during HIV, Reasons or stopping ART, Medical history, Linkage to NGOs, Pediatric patient, Investigations, Follow up.

2 Data entry operators are present to enter the data – one to prepare monthly excel sheet, other updating the CMS system.

Doctors never used to refer to the software for the data nor they had any computers present on their table. They used to do, routine check up, looking at the ART book & Screen cards.



5.3 Process of HIV diagnosis & treatment in Private Clinics

The person visits the clinic due to fever or typical symptoms that show his weak health. The doctors test him for HIV on diagnosis and the doctors maintain his/ her reports. He is given an I-Card that contains his registration number and is expected to get this I-card on every visit at the Clinic.

In the Private Clinics that I have visited there was very much less counseling done, compared to the Government hospital. The patients coming in at Private clinics have complete trust in the doctors. There are no specially recruited counselors, like those seen in Government hospitals. If the patient wants to include his/her family member and undergo counseling it is done. But 'Counseling ' is not a mandatory process as seen in the govt. hospitals. The main difference is that govt. hospitals undergo, Pre/ Post test counseling and also Pre ART counseling. There are also certain group discussions encouraged among patients and Outreach workers/NGOs are encouraged which is not seen at all in the private. Clinic scenario.

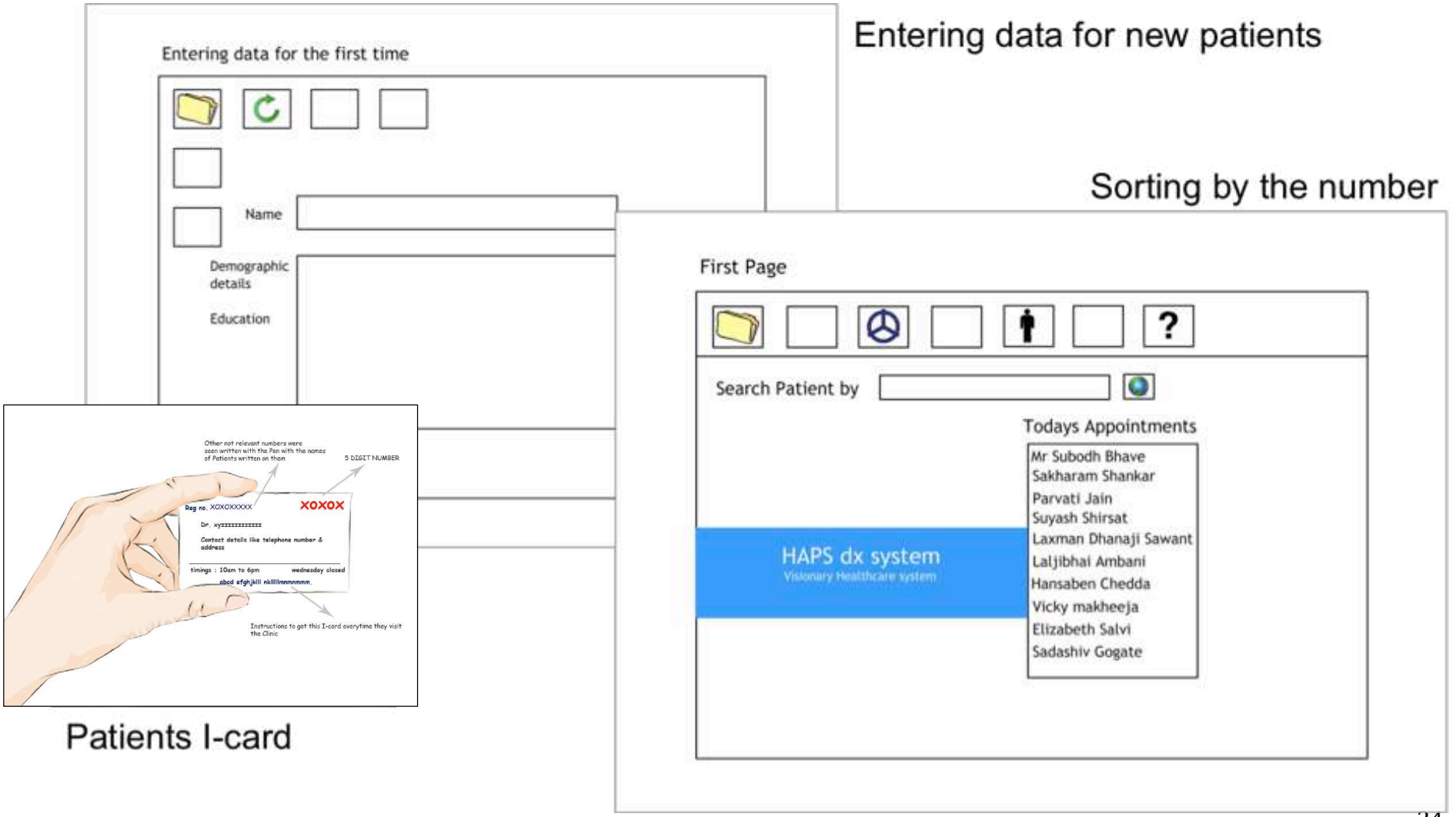
After reading the reports the doctor decides whether the patient needs to be on ART or not. Typically the patients having CD4 count less than 250 are started on ART. There is an Assistant doctor and the main doctor in the clinic. Generally the assistant doctors do the routine check up and diagnosis for the stable ART patients.

For the initial period when the ART regimen is started, patients visit the clinic frequently. Patients are charged for the treatment, unlike the government hospital. Patients are under observation for initial 15 days just like a govt. scenario.

The reports of the patients are maintained in the software applications / database of the doctors and a printed copy of reports is provided to the patients.

Patients are allowed to buy medications for ART from any Pharmacy or few patients even opt for government ART due to financial reasons. Doctors at Private clinics also refer their patients and encourage them to take free ART looking at the financial conditions.
Thus a lot of Clinic hopping is seen in the patients as they at times conduct tests in Private hospitals but take up ART in Government hospitals due to financial conditions or trust is also one of the reasons for the patients to resume to Private Clinic.

5.4 System Design in Private Clinics



5.4 System Design in Private Clinics

The doctors generally have H.A.P.S dx System where patients records is stored and it is used to keep track of appointments, analysis of data etc. But many of the features in the system were unexplored, as they did not give any prior information of its contents.

HIV AIDS patients Preventive Management Study

It consisted of Patient personal demographics

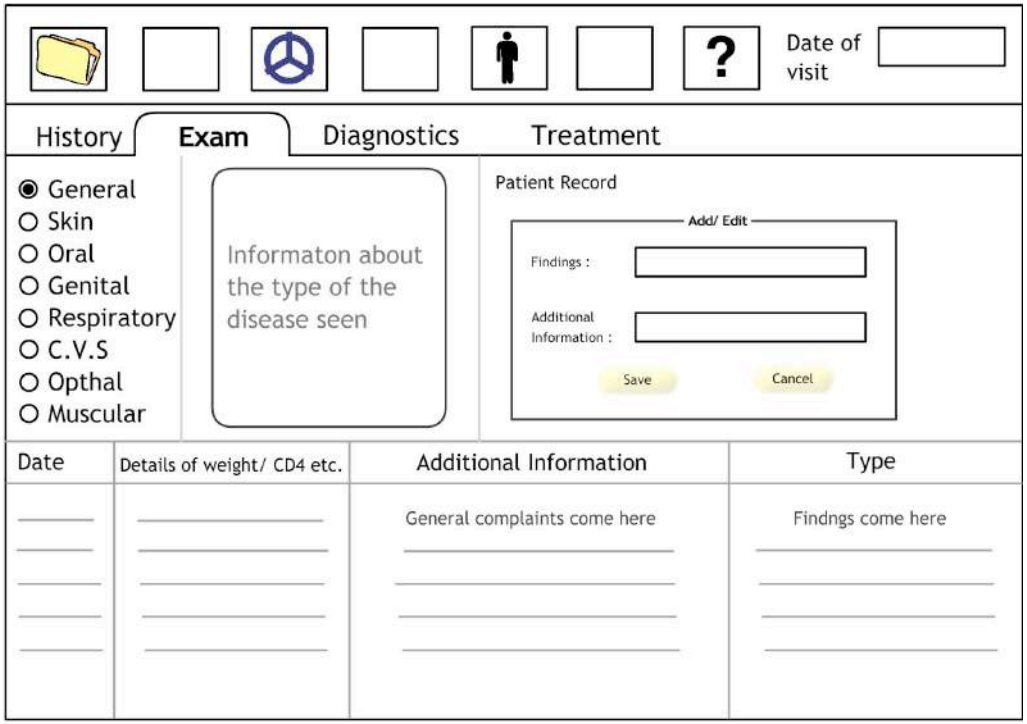
History – complaints, OI's (Opportunistic Infections), personal history, medical history, drug allergy, family history, social/psychological aspects. It had family details in it, like the number of members in the family, if they were tested for being positive or not, etc.

Examination – General, Skin, Oral, Genital, Respiratory, C.V.S, Ophthalmology & Musculoskeletal. The side effects if any were mentioned on the paper manually an just a remark was made in the system.

Graphical Findings: mark lesions findings on diagram of the body . This feature was unexplored.

Treatment – Drug prescription, test/investigation, Follow up, counseling & Reports (unexplored)Statistics – feature was never explored as one couldn't figure out what the tab/feature might contain and also as it was not much important to be explored separately as the other features also contained the same/ relevant information.

Patients Page



5.5 Information needed by Patients

Patients need to know if they are on ART treatment or not
It was seen that they are unaware of their status and at times not knowing the terms like ART, CD4, Viral load etc.

Regimen & Side effects
Patients should be well aware of what side effects may be caused by what kind of medicines.

Updates of CD4 count & Viral load
Patients don't tend to understand the meanings of those terms and thus are not able to relate with their status or well-being.

Medical History
They are unaware of their status and the health related changes, which they could share with the other doctors (GP)

Management of resources / expenses on treatment
Users were seen in low economic state where they are not able to visualize the expenses that they would face in the near future, or manage the resources for the same.

Reminders for medicine/doctors appointment/tests & reports-
Reminder for a medicine with a complex regimen is needed. Tracking doctor's appointment is difficult as it's scheduled after a month.

5.6 Information needed by Doctors

Patient's demographics
To know the details about the Patient, his health status, social and Psychological aspects, etc.

Medical History
To know if the patient had any kind of previous diseases or sufferings, drug habits etc.

Family details
To know about the family members, if they are tested positive or not, HIV status is disclosed or not, and any other medical implications.

On ART treatment or not
The patient is on ART regimen or not, his details about the same, as to when HIV was diagnosed and is on ART since what time.

Current status – side effects / regimen
If the patient is having any kind of side effects, changes in regimen and accordingly improvement in health.

Analysis of patients data / statistics
Doctors need to get reports of the analysis of patient data across various factors (age/CD4 count , etc.) in the application. The data should be generated according to the location, age, CD4 count, Viral load with respect to medication.

5.7 Existing Examples

An expert system for HIV & AIDS Information

This was an expert online system developed for the people of Botswana where they could ask for their query online wherever they are. It was aimed to be developed for the semi literates. This system proposed to provide general information about HIV and AIDS to these people. It solved the purpose of providing information and educating the public. [6]
(Figure 7 & Figure 8)

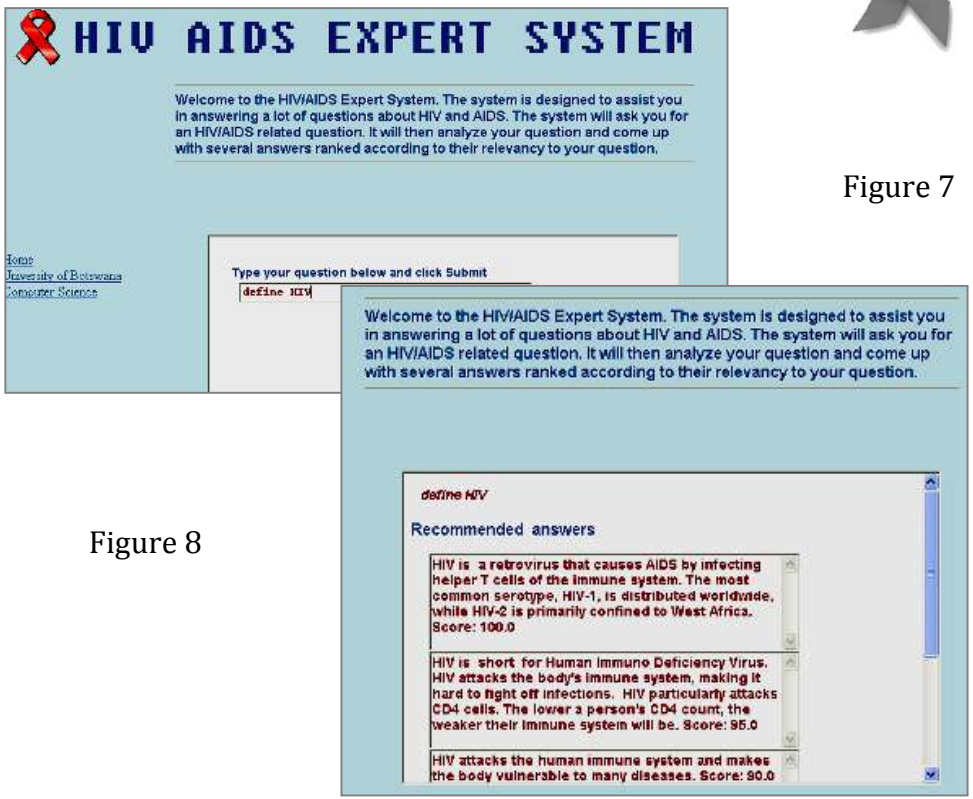
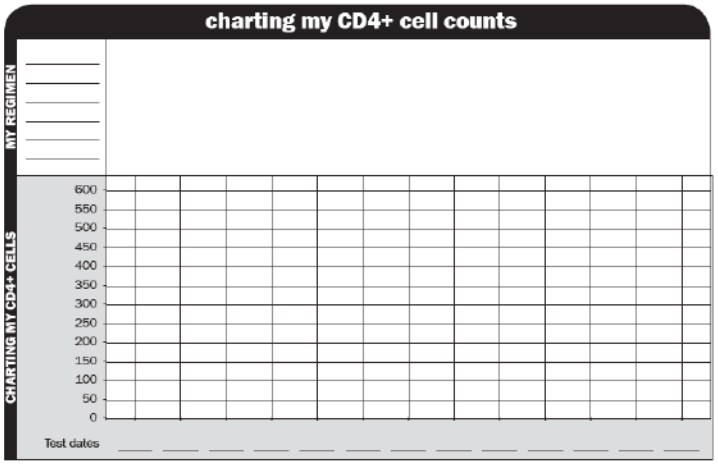


Figure 7

Figure 8

Personal tracking charts –personal tools that help you track your health

'Project inform' tried to think how people may deal with while taking medicines everyday. Thus they came up with various charts, in the form of printouts that one would use in daily life to keep track of their health and the ongoing history related to HIV.



keeping track of the medicines i take and have taken

Name of medicine or supplement	Start date	Stop date	Side effects I had/reason for stopping/other information
MEDICINES FOR HIV (viracept, retrovir, norvir, zerit, etc.)			
HIV-RELATED MEDICINES (bactrim, zithromax, diflucan, etc.)			
OTHER PRESCRIPTION MEDICINES (ativan, flonase, zoloft, etc.)			
PRESCRIPTION BIRTH CONTROL (ethinyl estradiol, etc.)			

People were suggested to take these charts with them, whenever they visit doctors, so that the patients could sit and discuss it with their doctors.

Going over together would help patients understand which medicines to take when and the procedure of taking medicine.

In addition to these charts, you will find a step-by-step diagram on the center spread, called *Walking your way through making a treatment decision*. This is a chart of basic information to use when making decisions about starting treatment. There's a lot to consider when starting treatment, as will a patient afford the ART regimen, is he/ she prepared to withstand the side effects caused by the medicine regimen, or is he/she aware about the fact that this treatment is lifelong. So the project tried to break it down for PLHA in the easy step-by-step diagram. [7]

how to take my medicines

At this time ...	I take these pills, liquids, or injections ... (put number of pills in parentheses)	And I do these things ...
___:___ am/pm	_____( ) _____( ) _____( ) _____( ) _____( ) _____( )	
___:___ am/pm	_____( ) _____( ) _____( ) _____( ) _____( ) _____( )	
___:___ am/pm	_____( ) _____( ) _____( ) _____( ) _____( ) _____( )	
___:___ am/pm	_____( ) _____( ) _____( ) _____( ) _____( ) _____( )	
___:___ am/pm	_____( ) _____( ) _____( ) _____( ) _____( ) _____( )	

EXAMPLE

8 :30 (am)/pm	Bactrim (1) _____( ) _____( ) Zithromax (1) _____( ) _____( )	Take Zithromax only on Monday, Wednesday, and Friday on an empty stomach with a full glass of water. Stay out of prolonged sun.
9 :30 (am)/pm	Combivir (1) Viread (1) _____( ) Rescriptor (4) Kaletra (3) _____( )	Make sure to take Viread with food.

A web-based self-monitoring system for people living with HIV/AIDS

This work has been carried out under the SEAHORSE EU project to build and test a Web-based self-monitoring system for HIV/AIDS patient care. The user interface had been carefully designed to provide a high-level of interaction and improve the limitations of Web applications.

The system comprised of three modules:

Patient self-monitoring personal diary, which could create a follow-up patient record; data analysis and visualization tool; and a section to allow patients to ask for advising and remote doctor support. [8]

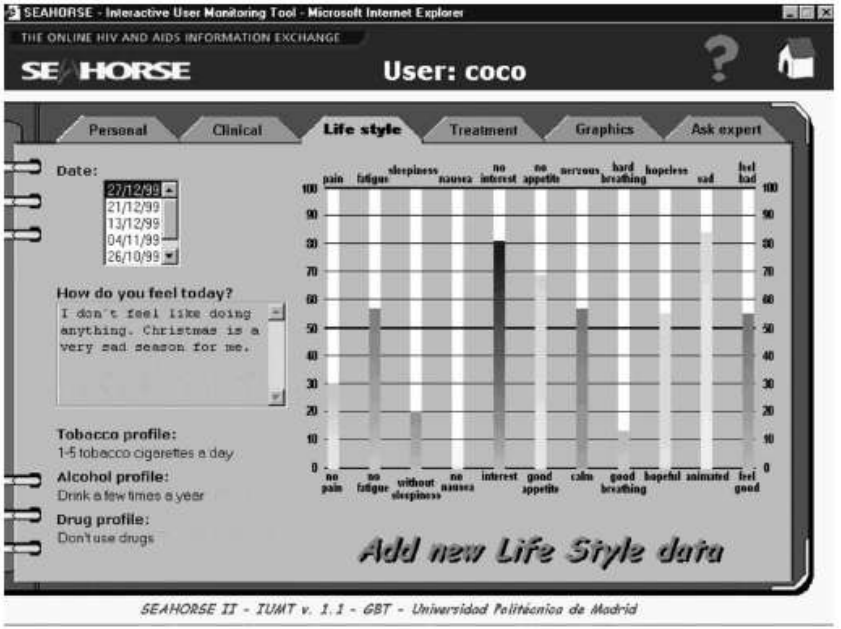


Fig. 1. Life style data visualisation.

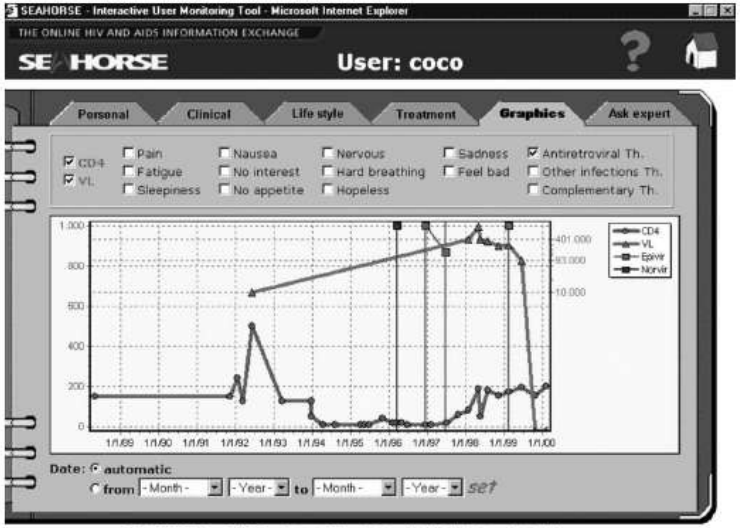
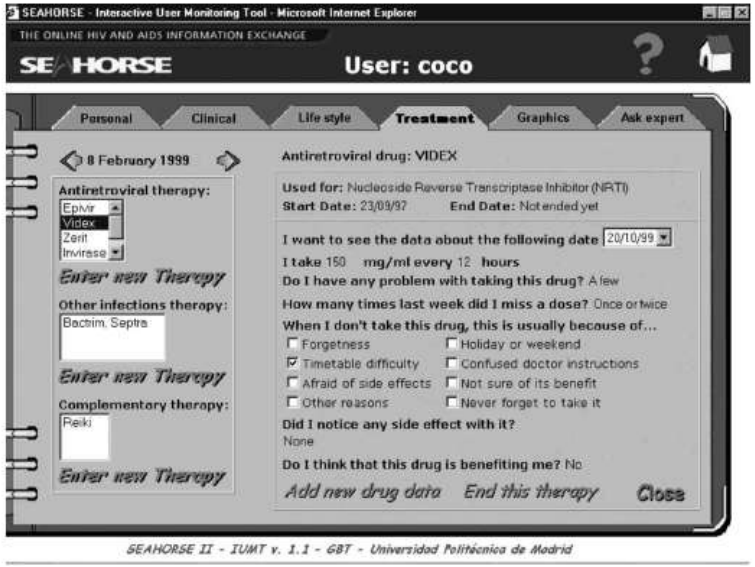


Fig. 3. Impact of two drugs on the CD4 and viral load levels.



6.0 Scope for Design

6.1 Observations & Insights

General Observations:

Patients carried cardboard files, only if they had done CD4 tests

The screen cards of the patients kept in the medical room of the govt. hospitals were lost.

Had to carry an I-card, which had a registration number whenever they had to visit the clinic, similarly patients from the government hospital had to carry the green card (ART book)

They like to maintain the confidentiality about their HIV status but on reports their status is mentioned in bold letters.

Clinic hopping was seen amongst the PLHA. Patients used to hop between clinics due to the treatment related issues such as, losing trust on doctors or going by others experience. There were financial reasons involved too.

Postcards are kept in every patients folder, to follow up if the patient discontinues the treatment

System should be User friendly and the data analyzed in a statistical format in software should be easy to use & understand

The CMS system present in govt. hospital has similar details those are present on screen card. CMS system is widely used by the government hospitals. It is approved by NACO.

There are link ART centers attached to the govt. hospitals were stable patients are transferred

The computer in the govt. hospital had webcam attached to it, to scan the photograph of the patient.

For every patient doctor had to suggest appropriate Nutrition. (Orally suggested diet and importance of exercise) Thus had to speak orally the same thing most of the times.

There are two Data entry operators present to enter the data – one to prepare monthly excel sheet, other updating software.

Specific Observations:

Patients thought that CD4 changed due to their Nutrition

Patients have trust in Doctors (Private clinics) were ready to take medicines from govt. hospitals but were reluctant to have tests done, in those hospitals.

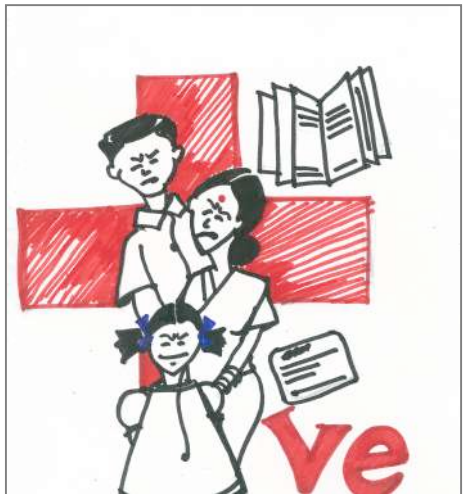
They hide the reports at home, so as keep the confidentiality

Many features of the system were unexplored – graphical findings, reports, printouts, statistics etc. as they were not understood and were not very relevant.

System used to take time to load the clinical data

Doctors used to save patients data on Flash drive separately everyday for the purpose of taking a backup.

Doctors never used to refer to the software for the data due to eyesight related issues, or the information was provided on the second level of the interface.



6.2 Problems & Scope for Design

People are not aware that managing the reports is an important factor. The reports are burnt, torn off due to non disclosure or stigma issues and are misplaced or stolen, at times as they are traveling from far away distance, to visit the clinics.

At times there are 2/3 family members suffering from HIV – they all file the reports together, this creates confusion and also, the PLHA carry all the reports of family members as they are not able to recognize their own report.

I- cards are lost or stolen which causes problems as they need to show these I-cards on every visit to the clinic.

Patients tend to forget next appointment that comes after a month, need assistance to remember and also medicine reminders etc.

Trust doctors and are confident that they maintain their reports.

At times patients get side effects of certain doses, and so have to wait till next appointment date to meet up or travel and meet doctor to change the regimen.

Confidentiality is not maintained as printouts have +ve status mentioned in bold letters on the reports.

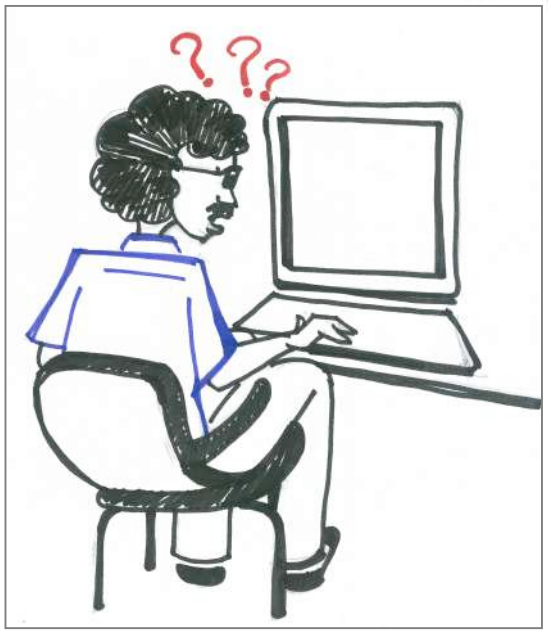
Doctors have to explain the Nutrition related information for every patient that visits the clinic.

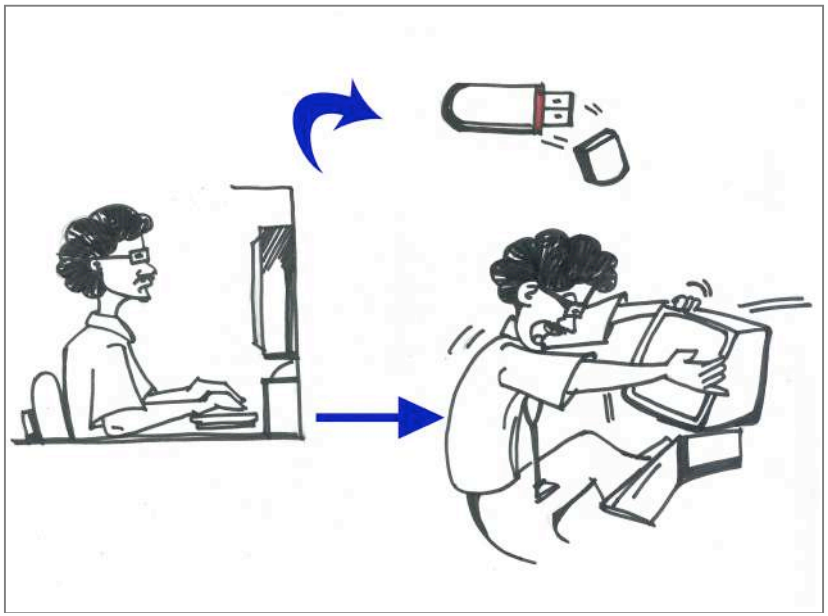
Many features of the application/software are not explored or understood by the doctors like graphical findings, reports, printouts, statistics etc.

They have to always write a feedback on the paper manually for every patient and even feed in the details in an application. They get tired in the process

Have to take a backup of the data everyday on the Flash drive if its not taken, and the data is lost it can be very critical.

Analysis of the patient's data & clinics data is not very clear and can get confusing.





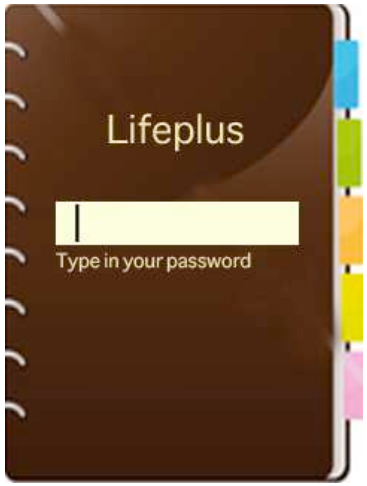
7.0 Initial Ideation

The need and scope for design to provide information to the patients suggested developing an application on a cell phone. This would be a personal device and even if the mobile must be shared, the application developed would be password protected.

This had a "Diary" metaphor as the user could relate very well with the same as they were encouraged by the doctors to maintain a diary for the health problems, sharing thoughts etc.

'Lifeplus' – A mobile application that would provide information to all patients suffering from HIV.

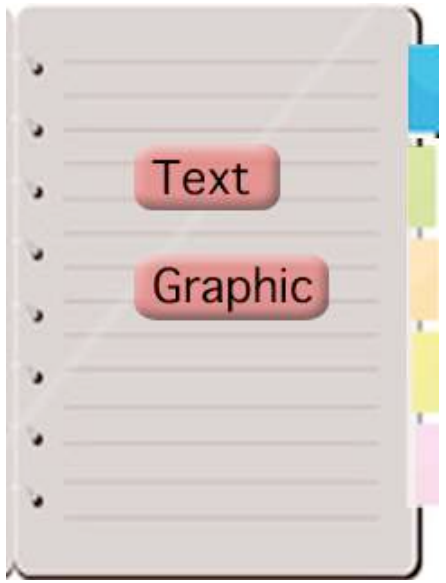
It would keep them updated about their current status and help them plan and organize an appointment and would be loaded with many other features. This prototype is being generated using **Flashlite 2.0.**



Login screen is password protected

It has various features as –

Reports to view Text /Graphical output Of CD4, Viral load counts or other tests.



History – It would provide medical history of past months which would help sharing of health related information to general practitioners /doctors.

Scheduler – This would have two sections – medicine reminder & Doctors appointment

Side effects – Here information related to the side effects would be found & reporting side effects to the doctors would be the other feature.

Expenses – This feature would help patients to get an overview of expenses on medicines and/or tests which they would have in near future.

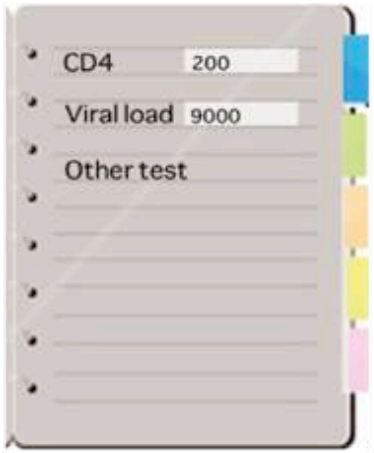
As it is a tab based design it has been further iterated, as the text on the tab, wouldn't be visible. The idea was to make the features hierarchical so as to give importance for the important information first.

Reports feature in application

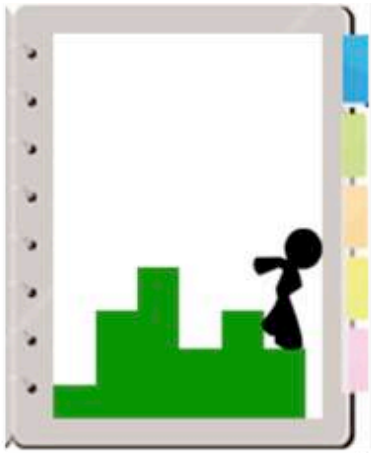
As the patients never carried the reports with them, it would be a great feature to have it displayed on the cellphone.

This feature would have options for the display, in various formats, as text or graphically.

Patients mention “CD4 Kami zalay” or “CD4 jasta zalay” ie they are just able to relate the CD4 count as High or low /less or more.etc. This feature would thus display the CD4 count and Viral load visually in an abstract format that would be easy to understand and would be represented in the simplest form. The steps to be climbed was given a preference as it shows the current status is better than earlier, very clearly.



Text output



Graphical output
Steps going up/down
metaphor

Graphical output
waves going up/down
metaphor

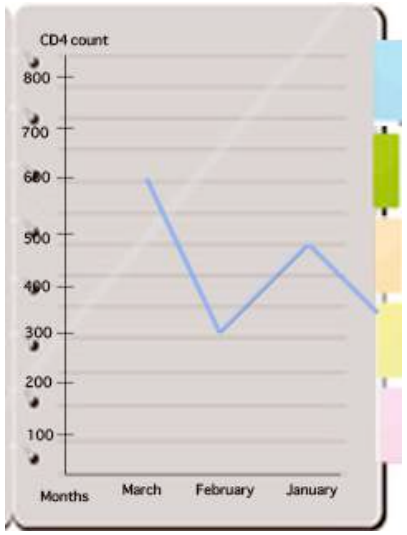
More smiles, less
Frowns metaphor

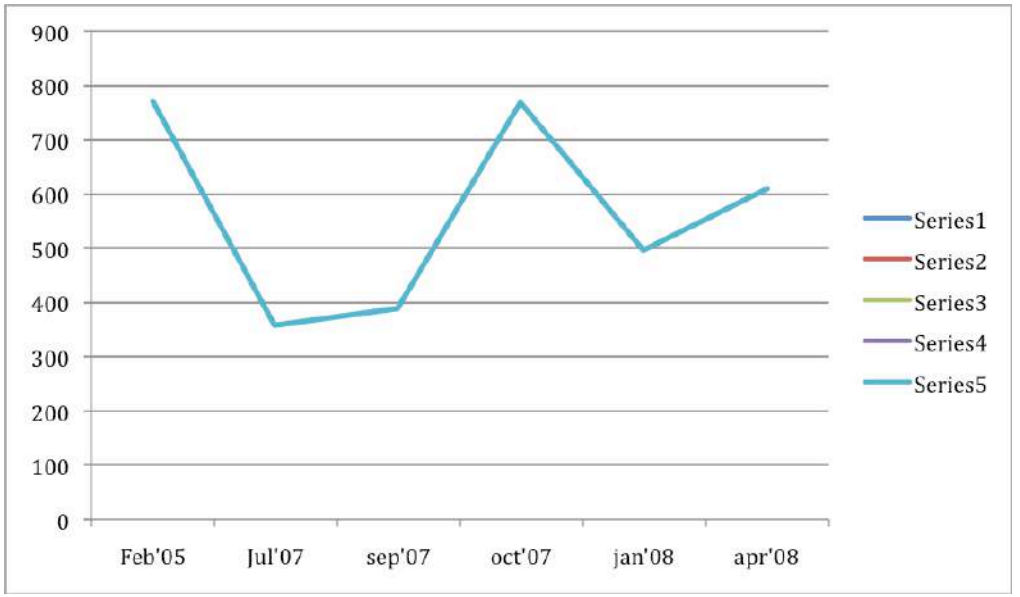
History feature in application

This feature would display the statistical format of the graphs, ie of the CD4 across the months, or viral load across the months with respect to the medication/ regimen.

This feature is present so as to share the data or medical history with the general practitioners. Patients do occasionally visit the GP due to other infections or diseases like diabetes etc. thus sharing of their history becomes a critical issue, and if patients are unaware about their status or are not able to explain their current status this feature would be very helpful for them.

The data could be transferred via Bluetooth or by the application or could be just shown through the cell phone. It would have further options to browse data according to the last done CD4 months & years details.





Scheduler feature in application

This feature would help schedule the important reminders for the complex regimen or even to fix up an appointment.

'Medicine reminder' would help patients to set up an alert for medicines. The regimen would be automatically updated in the system – patient will have to just set the time. It would show the picture of current regimen (medicines), when it is to be taken & the procedure of taking. There are other factors to be considered with the same, as for example a scenario of missing a pill, or if the pills are over. There would be specific alerts for these scenarios.

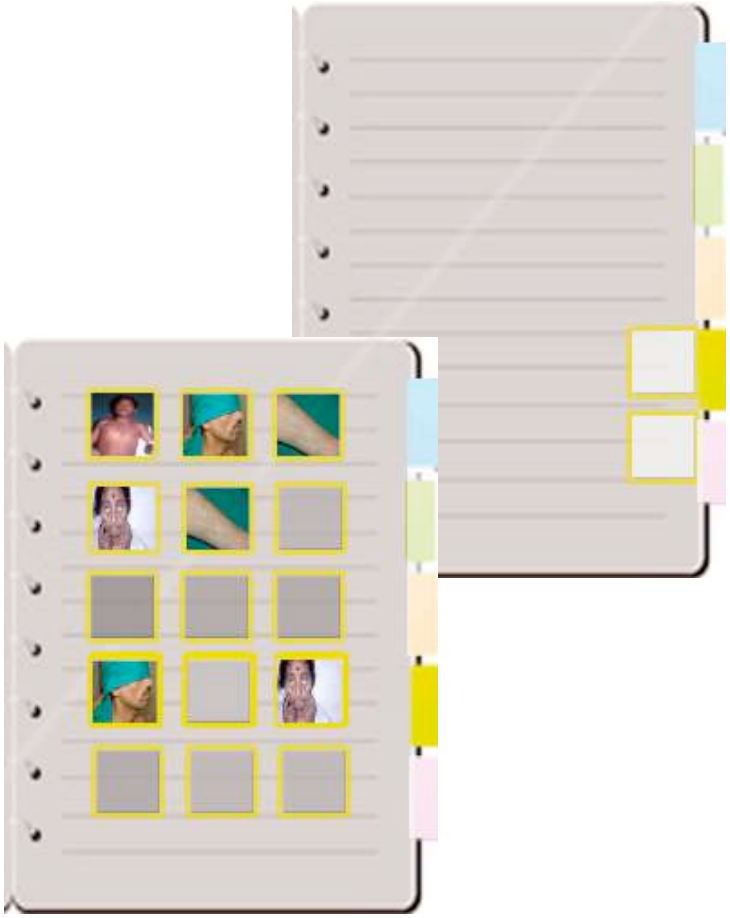
'Doctor's appointment' would help patients to set up an alert for the appointments. It would help schedule/ change an appointment in case of emergency. This feature would send details to fix up appointment by selecting a date from the calendar, if its available immediately the update would be sent or it would suggest to select another day.

Side effects feature in application

There are situation when patients feel unbearably nausea tic, or get some other side effects and get tensed about the condition, in such a situation this feature helps to report side effects to the doctor immediately.

"Pictorial form" would help patients to select the form of side effects by matching it through visual and report to the doctor whereas the "Description" method would require patient to type in the details. This would be sent as an sms, that would be stored in a database. After selecting the side effects picture it would ask for any other possibility of symptoms that you feel you may have. It would thus send the data and update the related information if the specified drug regimen shows the similar side effects.

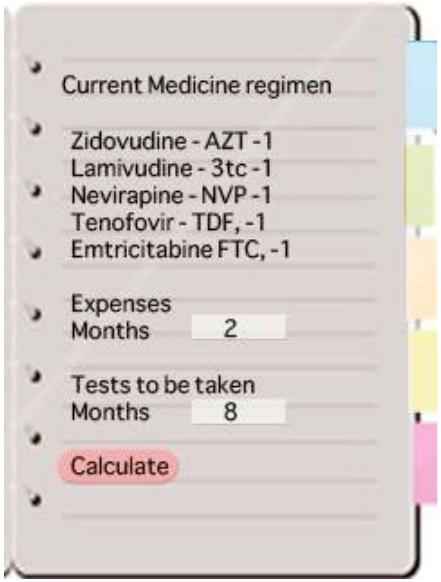
Or else doctors appointmnet would be scheduled and a reminder would be set up for the same. This interface would be visual + text and audio is not being used so as to take take the confidentiality aspect of HIV as patients wont like if the audio would play loudly.



Expenses feature in application

Expenses feature would give a quick overview of the expenditure on medicines and /or treatment. The patient can suggest if he is taking free ART & medication or Private ART and free medication and so on. There would be different profiles of users having different expenses.

It would also include details about tests to be taken and expenses for the same for eg. CD4 test needs to be done every 6 months, thus it would provide the patient and overview of future expenses. One could be able to calculate the expenses occurring in future.

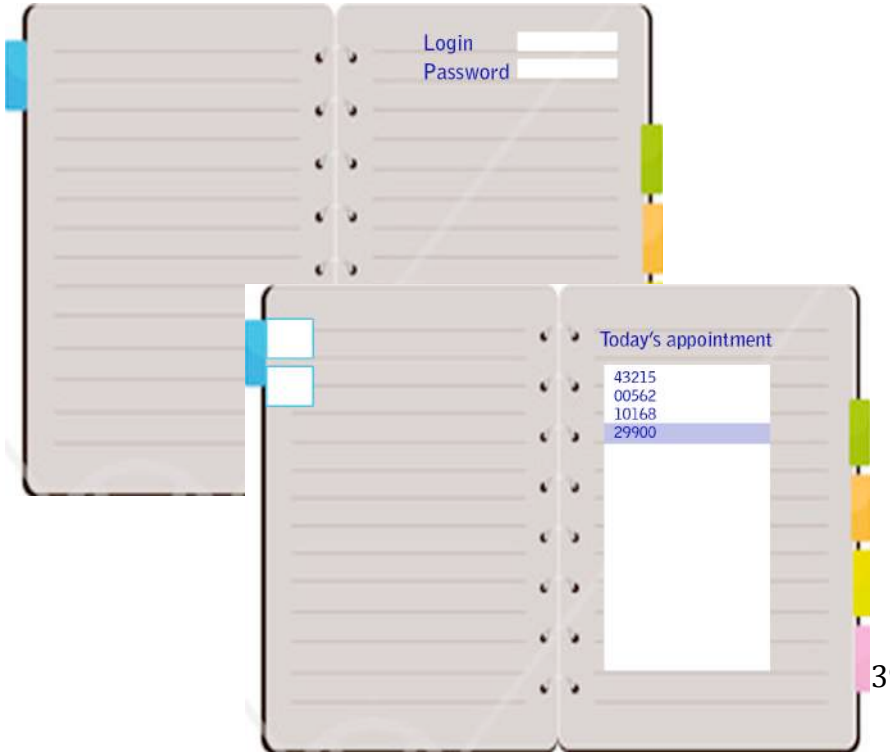


Application for Doctors

Application for doctors can have metaphor of a "diary". This was an initial thought but understanding what is relevant and important for doctors this has been modified and a simple interface is being developed, using **Axure** software.

It would be password protected, would start with a Login screen

When the Doctor logs in, he would land up on the Todays Appointment page, where he see's the appointment – denoted with the 'numbering'



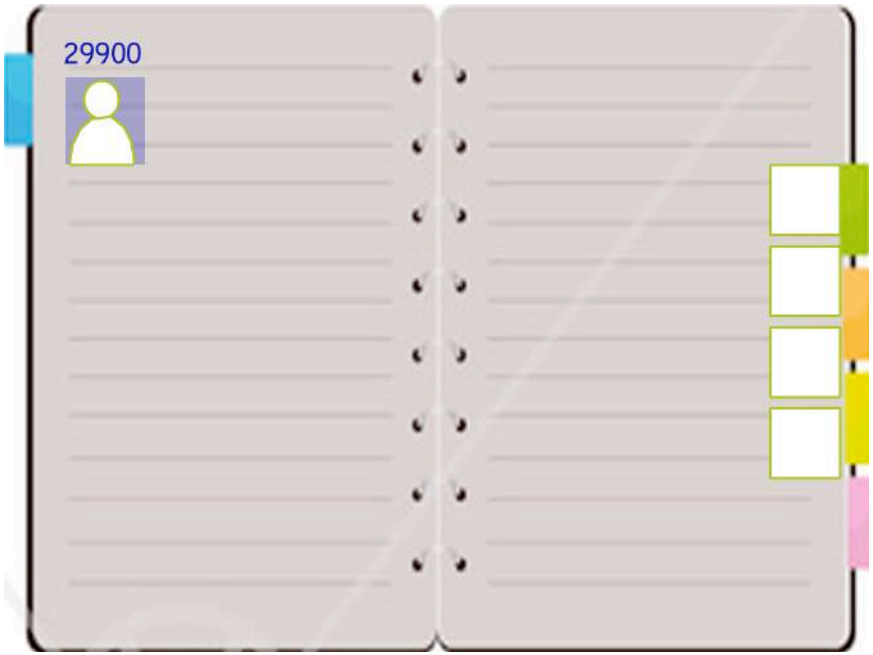
Primary categories would be Patient Profile, Family Profile, Analysis, Search

Patient profile consists of details/Psychological aspects/Social aspects/ Medical records

Family profile - details/Psychological aspects/Social aspects/ Medical records

Analysis – statistics according to age, location, drugs, CD4 counts etc.

There would be a section of updates where the updates or queries from the patients would be stored so as to be answered by the doctors. It would have priority filtration based on the question asked.



Concept 2:

"LifePlus" concept – This is an iconic mobile application that would give a quick look of all featured & important aspects at a glance. Highlighted things would be given as a summary eg. Critical patient, urgent appointment due to side effects, etc.

Mobile application would appear in similar format.

- Reports
- Medical History
- Scheduler
- Expenses
- Side effects
- Speak up – This would be a platform for the patient to share his views ideas or anything that would be social or say psychological issues or matters that need to be discussed. This would be a feature to express one's mind and would include instant calling (IVR) system that would answer the FAQs of patients. Or it would have 'share' option to share specific information or post a question.

Desktop Screen would consist of all the icon based features or a menu item.

Highlights would appear below, which would be combined updates across the features. These highlights would appear when one menu item from the iconic list is selected.

On clicking one can browse through each feature separately

Other concepts:

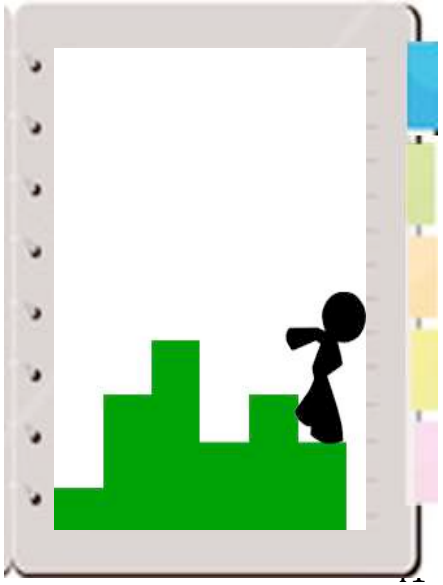
After the pictorial representation random questions related to Health/ Nutrition can be asked where user answers to get results (Interactive game)

Remarks for encouragement

Sending messages/ Audio output to the patients cell phone – Info related to Nutrition or other details.

If the CD4/ Viral load count / side effects or other conditions of patients match, Result or info could be displayed on screen, this can give a better comparison.

Graphs of CD4/ Viral load changes according to months & details of medicines



8.0 Final Design

The final concept in development. 'LifePlus' comprises of Icon based application with text on the cell phone for the patients. This prototype is being made using Flashlite and a neat clean interface for doctors that is being developed using Axure software.'LifePlus' application for patients is iconic and works on the numeric key press. Each icon is assigned a number, which would help it navigate easily, and also it would make it easier for the patients to use it. Once the numbers are remembered according to the features it would be easy for the patients to navigate.

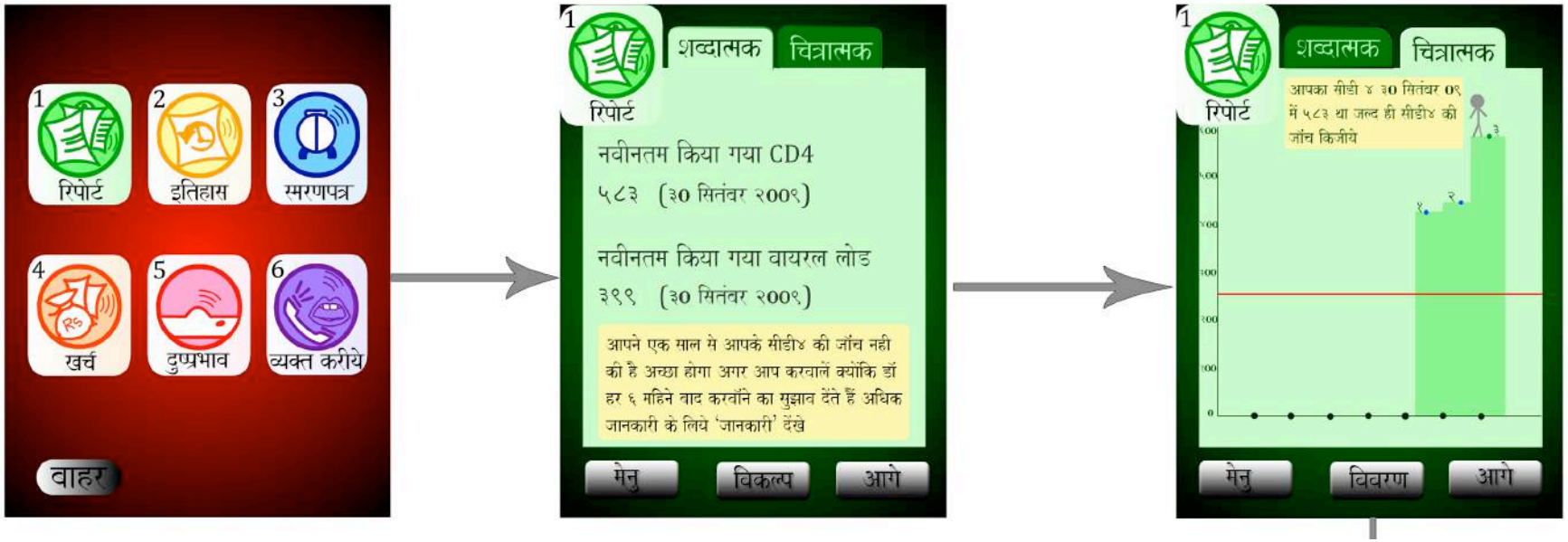
The desktop screen contains 4 major features – Reports on 1 key press, History on 2 key press, Reminders on 3 key press, Expenses on 4 key press, Side effects on 5 key press and speak up on 6 keypress. The interface is made using 'Hindi' language as it would be easy for the patients to read and use the application. The mobile application is visual and text based, and audio is not included determining the fact that privacy & confidentiality is the main concern of PLHA. Lets consider various task based scenarios of the patients using this interface.

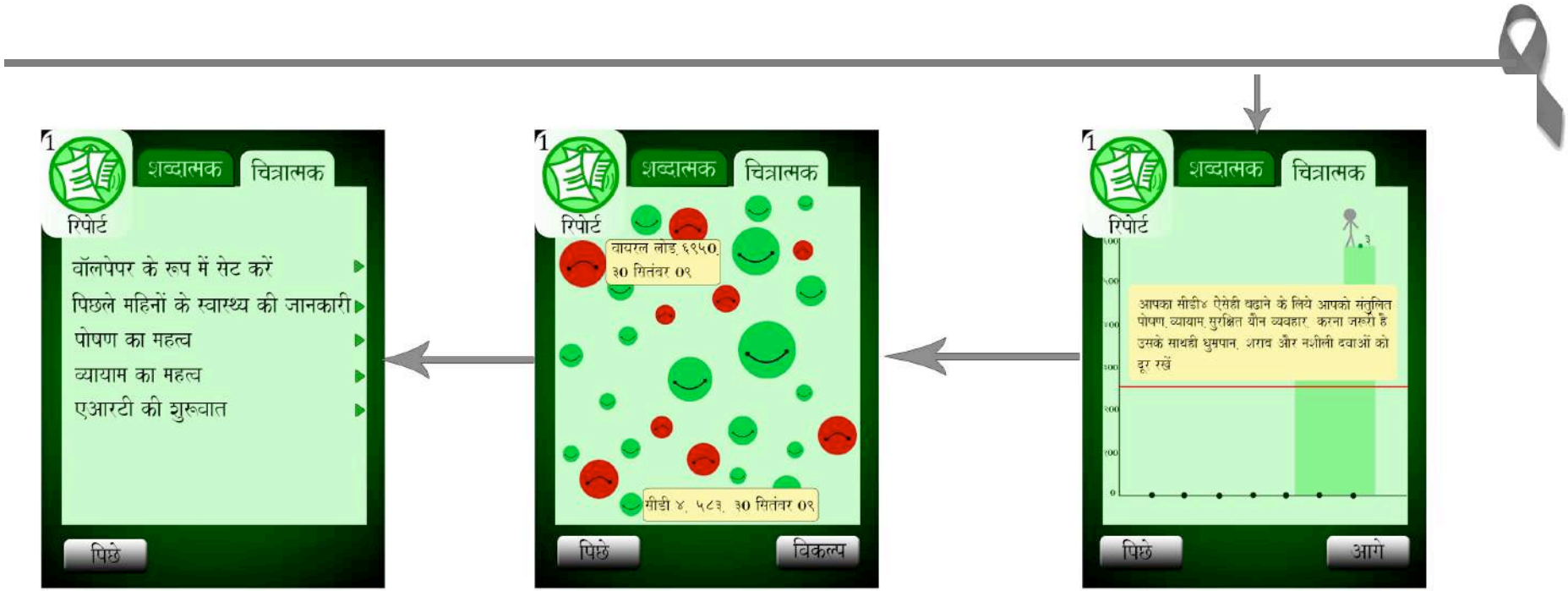
Scenario 1:

Radha has been detected HIV positive, she is said to be in Pre ART state. But she doesn't understand her status. She doesn't save the reports due to disclosure issues and requires a lot of information as to what her current CD4 count is but doesn't understand the reports. She wants to know how her CD4 can be increased and so on and she has heard about ART but needs to know what exactly it is.

She is given a mobile application "LifePlus" when she has been detected HIV positive. She see's that some features are 'activated' by the doctor like Reports, history , speak up and Visit section in reminders, while others like pill reminder, side effects are not activated in her application as she is not on ART.

She can very easily access reports on this application. Get to know the Health, nutrition related details and what is initiation of ART.





Scenario 2:

Ram who is HIV positive and is on Pre ART stage falls ill, and is suffering from tremendous back pain and severe headache, fever & Nausea. He decides to visit the nearest GP .The doctor diagnosed it to be TB and asks about the medical history. Ram is not able to describe his current status, details about CD4, viral load count etc. but he remembers he has an application through which he could share the data to GP.

Ram thus uses “LifePlus” application and presses the button ‘2 on the keypad’ that is assigned for ‘History’ feature. The data in graphs format is displayed on the screen and can be browsed according to the months. In this manner the Ram is able to share his status and medical history of HIV. Now he can send the data through Bluetooth or just show the graphical representation of medical regimen, compared with CD4 and viral load counts.


1
रिपोर्ट
2
इतिहास
3
स्मरणपत्र
4
खर्च
5
दुष्प्रभाव
6
व्यक्त करीये
वाहर
इतिहास
नवनितम किया गया सीडी ४
१५४, २३ फरवरी ०९
नवनितम किया गया वायरल लोड
६९५०, २६ मे ०८
अभी दी गई दवॉईयॉ
फोलीनिक एसीड, पाईरेमिथेमाईन,
फ्लुकेनाझोल, डापसोन, टेनोफोविर,
झायडोव्युडाईन, लामिव्युडाईन
मेनु
विकल्प
आगे
इतिहास
CD4
मेनु
विकल्प
आगे
इतिहास
CD4
मेनु
विकल्प
आगे
इतिहास
प्रिंट
भेंजे
ब्लुटुथ
ईमेल
मेनु
पिछे
इतिहास
डॉ. को सीडी ४ की जानकरी
भेंज दी गई है
मेनु

Scenario 3:

Sita is on ART since two months now, earlier she used to forget taking pills occasionally and needed someone's assistance to remember the pills and even hospital visits at times.

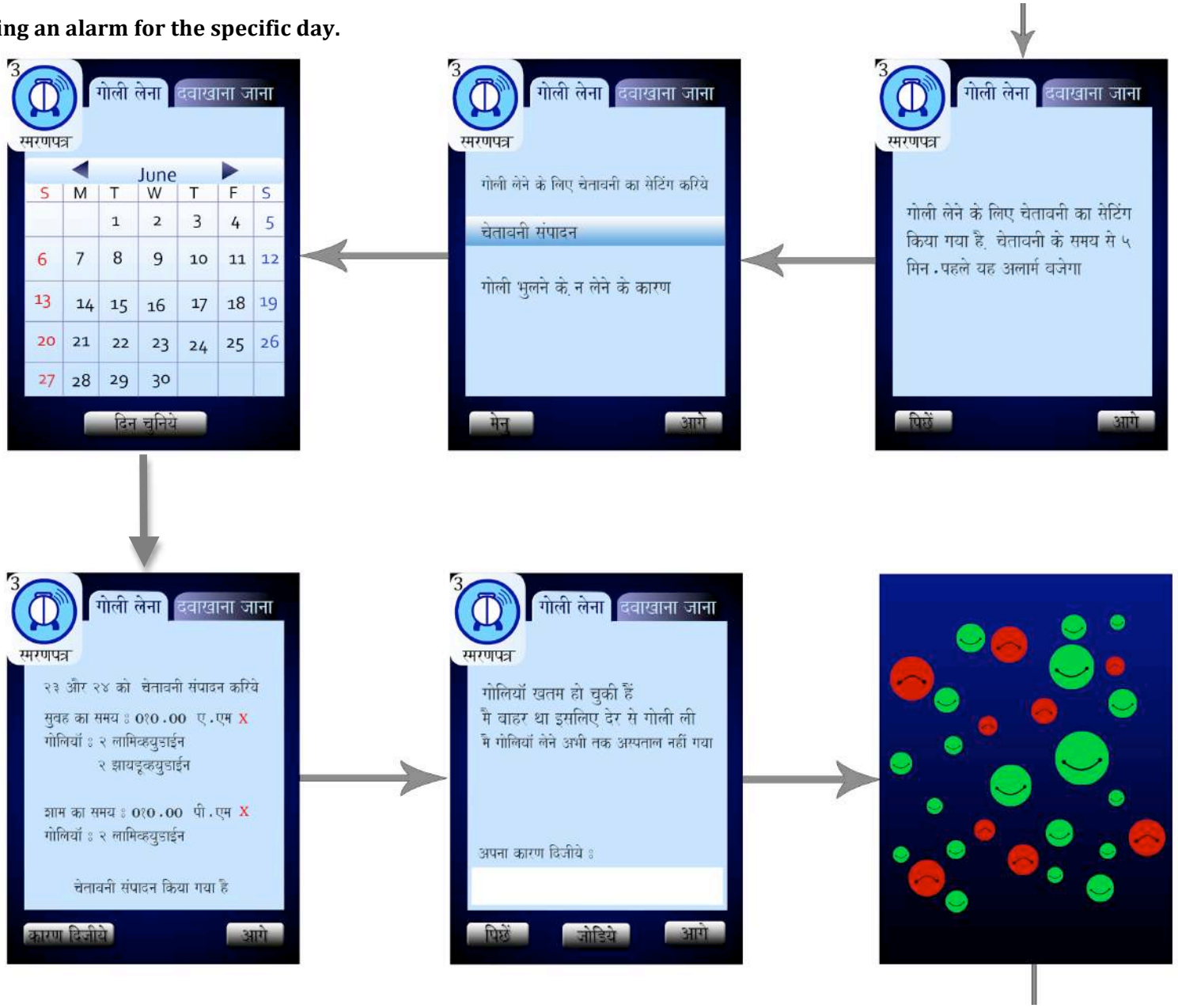
She has this application with a "Reminder feature" activated by her doctor recently after she went from Pre ART to on ART status. This feature/ menu is the 'LifePlus' application helps her by giving a pill reminder and a visit reminder updates prior to the pill taking time or the clinic appointment.

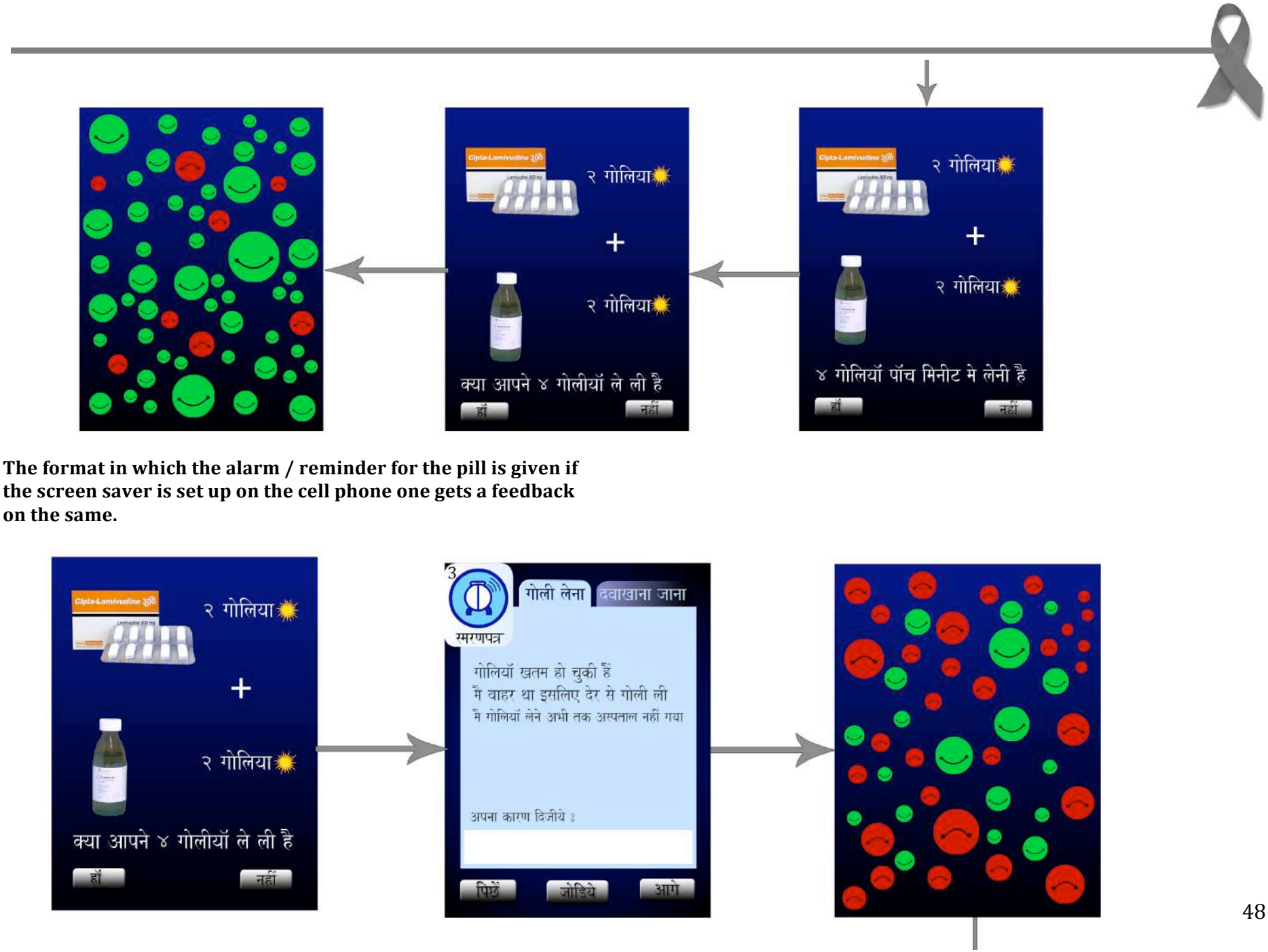
Pill reminder lets her know she is on which regimen, and when its started. Thus it informs her by showing a visual of medicines and the dosage to be taken. The reminders can be set by her manually once when she gets the medication. Applications works by sending a beep like a "nokia tune" 5 minutes before the pill taking time, (it indicates if its a morning pill by denoting 'sun' or night pill by denoting 'moon')

The interface after 5 minutes asks if the pill has been taken and immediately shows the current pill count. If anyone misses the time, it keeps on giving alert after 1 hour, (twice in a day) so that the reason could be entered in the database.

If the patients click 'Yes' the number of tablets left to finish would be given with the encouragement remarks like – "Just 10 left to finish the dose"
If 'No' is clicked the reasons chart would flash up asking to fill up the reason for missing or not taking the pill.

Editing an alarm for the specific day.





The format in which the alarm / reminder for the pill is given if the screen saver is set up on the cell phone one gets a feedback on the same.

Scenario 4:

(Above given) Shashi needs his daughter to remind her when exactly is the clinic visit scheduled. Now he doesn't need to depend on anyone as he has the visit reminder feature in his cell phone.

Visit reminder is a feature that never lets him/her miss an appointment with a doctor. This reminder helps him to be adherent to the current regimen, which maintains a good health. This feature would display a calendar where reminder could be set.

Task would be setting a reminder for appointment. Reminder would have 2 options – setting a reminder, editing a reminder.

Task of how a reminder would work.
The reminder would ring up, beep 1 hour prior to the appointment time. This would suggest that the appointment to visit a clinic is approaching near. There would be option of 'Yes' & 'No' stated if the PLHA clicks on 'No' then the clinic would be intimated immediately, so that they would follow up for missing the visit same/next day.

Setting a clinic visit reminder & how it would work


3
स्मरणपत्र
गोली लेना
दवाखाना जाना
दवाखाना जाने के लिये निर्धारित किया गया है. आपके लिये एक अनुस्मारक सेट करना चाहतें है ?
मेनु
हाँ
आगे
कल के लिये दवाखाना जाने का निर्धारित किया गया है
हाँ
ना
एक घंटे मे आपको डॉक्टर को मिलने जाना है
हाँ
ना

Scenario 5:

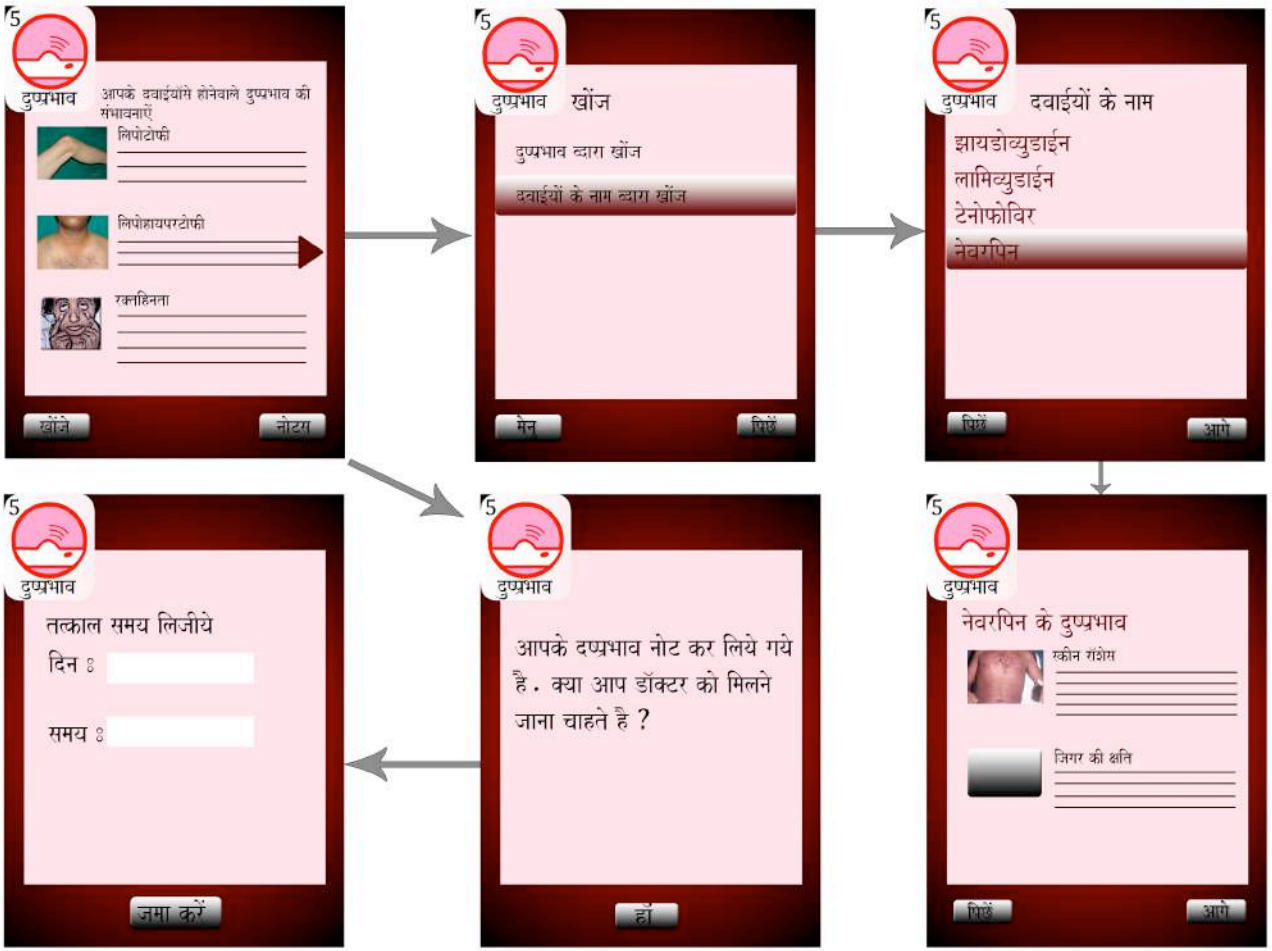
We have Sunil a HIV positive patient who is on ART since 2 years and he is not able to manage the expenses and lives on very low resources but wants to take medication from trusted source and so opts for a private clinic . He has to sell his cows for the same purpose and fears that next month too he will have to sell a cow. He tries to explore “Expenses feature” and is very happy as he is able to estimate the tentative expenditures that could occur.

One gets a quick preview of the current regimen with the expenses for a month and thus easily one can estimate the future expenses that he has to take care. This feature would give preview of the test expenses too, which are carried out once or twice a year.

Scenario 6:

The patients gets rashes and itching all over the body, and is worried what went wrong, as just the previous day he had got new ART medicine regimen. He has been on ART since long. He needs to know which side effects can occur due to the new medication and thus uses the "Side effects" feature to look up for the information about the medication and its complications.

Thus "Side effects" feature on the cell phone guides a person to get acquainted with the regimen and its side effects and in emergency also helps the PLHA to report it to the doctors.



Scenario 7:

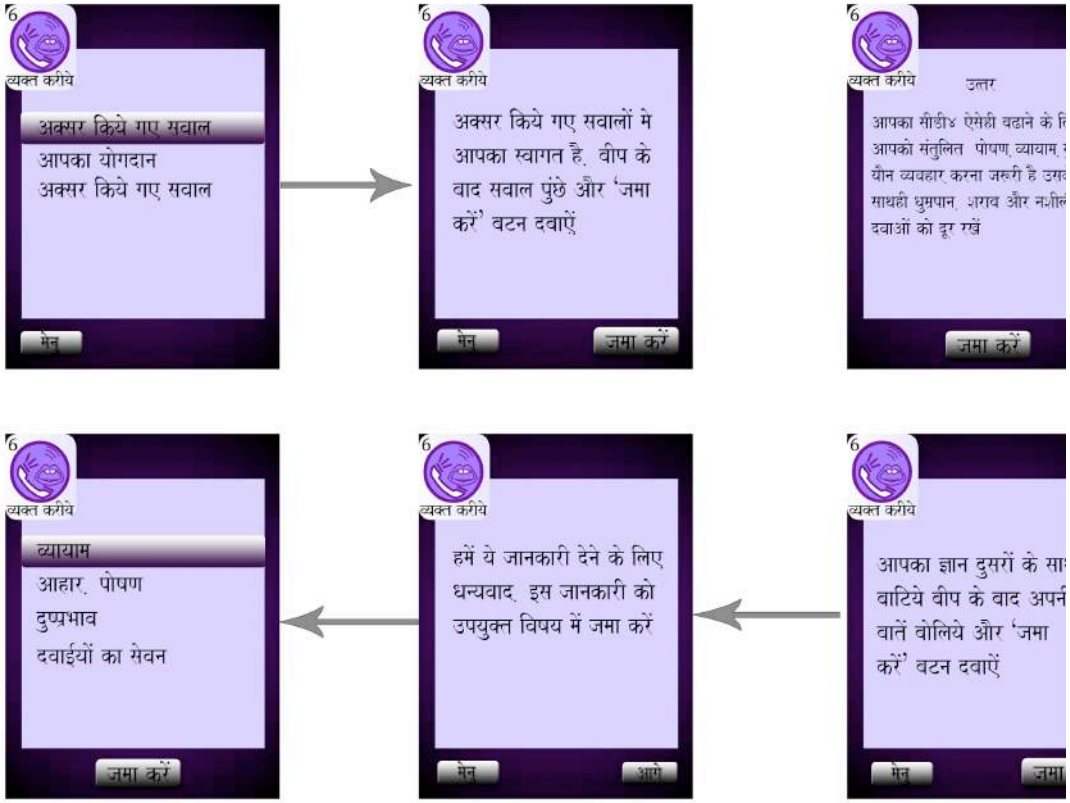
The patients are confused about certain things, let it be general or very factual information, thus they seek help from counselors, etc. but still many times the question remains unanswered. There are many HIV people who have knowledge about certain things like, regionally known nutritious food, that could benefit ones health.They also have knowledge about many things related to HIV and they don't tend to share it, so there's a need for an application, which would cater to these needs.

"Speakup " feature helps the PLHA to express himself and even lets him share any important information that other PLHAs wont know. It could be nutrition related or about any events etc. The other feature is FAQ where the PLHA could ask question and if the answer is available, he would be able to hear it back, or it would be saved in the queries of patient profile, which a doctor could look up and answer the next time he visits the clinic. Theres a Note section where all important information would be stored and can be accessed anytime.

There would be two inbuilt features in it- 'FAQ' and 'Share' & 'Note taking' for archiving. It would contribute to reach many people or network, providing information anonymously. 'FAQ's' would connect to the call where the PLHA would ask a question, if the relevant answer is available it would be read out.

After the last screen if the answer relevant to question is available it would play the answer for the user.
So also "Share" has different sections where the PLHA would choose, where his information is relevant and would record the information.

This would be stored in the database, and would be accessible through FAQ's to others



9.0 References

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10.0 Abbreviations

AIDS - acquired immuno deficiency syndrome

ART - antiretroviral therapy

ARV - antiretroviral drug

AZT - zidovudine (also known as zdv)

CD4 - T-lymphocyte cd4+

ddl - didanosine

GP - General practitioner

HBV - hepatitis B virus

HCV - hepatitis C virus

HIV - human immunodeficiency virus

NACO- National Aids Control Organization

NRTI- nucleoside analogue reverse transcriptase inhibitor

OI's - Opportunistic Infections

PLHA - People living with HIV AIDS

TB - tuberculosis

WHO - World Health Organization